Disparities in NIH funding for epilepsy research

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ABSTRACT

Using data from NIH Research Portfolio Online Reporting Tools (RePORT) and recently assembled prevalence estimates of 6 major neurologic diseases, we compared the relative prevalences and the annual NIH support levels for 6 major neurologic disorders: Alzheimer disease, amyotrophic lateral sclerosis (ALS), epilepsy, multiple sclerosis, Parkinson disease, and stroke. Compared to these other major neurologic disorders, epilepsy research is funded at a persistently lower rate based on relative disease prevalences. Relative NIH funding for these other disorders in 2010 adjusted for prevalence ranged from 1.7x (stroke) to 61.1x (ALS) greater than epilepsy. The disparity cannot be explained by differences in the overall impact of these diseases on US citizens. Greater transparency in the review and funding process is needed to disclose the reason for this disparity. ***Neurology*® 2011;77:1305–1307**

GLOSSARY

AD = Alzheimer disease; **ALS** = amyotrophic lateral sclerosis; **MS** = multiple sclerosis; **NINDS** = National Institute of Neurological Disorders and Stroke; **PD** = Parkinson disease; **RePORT** = Research Portfolio Online Reporting Tools.

The mission of the NIH is to "seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce the burdens of illness and disability."[1] This mission is addressed in large part by conducting and supporting research into the causes, diagnosis, prevention, and cure of human diseases. The NIH is a major source of funding for medical research in the United States.

Recently the NIH, and its neurologic branch, the National Institute of Neurological Disorders and Stroke (NINDS), launched 2 major initiatives. One initiative aimed to inform the public and research community about the types of projects for which it is providing funding. The second initiative, specific to the NINDS, aimed to determine the incidence, prevalence, and burden of 12 major neurologic diseases. The availability of data from these 2 sources allowed us to compare the NIH research portfolio with disease prevalence, and thus to determine whether funding was proportionate. In this article, we present our findings.

At the request of Congress, the NIH developed and implemented a process in 2008 to improve consistency and transparency in the reporting of its funded research. The Research, Condition, and Disease Categorization (RCDC) system uses sophisticated text data mining in conjunction with NIH-wide definitions to match projects to research categories, which represent the NIH's best estimates based on the category definitions. NIH estimates of funding for various research, condition, and disease categories are provided by the NIH Research Portfolio Online Reporting Tools (RePORT) from 2007 to present with estimates for 2011.[2]

Representatives of the NIH and the Centers for Disease Control and Prevention conducted a comprehensive review to estimate the current incidence and prevalence in the United States of 12 major neurologic disorders.[3] Their investigation provides the strongest available data on the relative occurrence of these diseases, and summarizes evidence that the burden of neurologic diseases affects millions of people in the United States.

METHODS Based on the 2 above sources, we examined the relative prevalence, numbers of affected people in the United States, and annual NIH support levels for 6 major neurologic disorders: Alzheimer disease (AD), amyotrophic lateral sclerosis (ALS), epilepsy, multiple sclerosis (MS), Parkinson disease (PD), and stroke. These neurologic disorders were included because individual

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Table Prevalence, number of patients, and NIH funding for 6 neurologic diseases

Disease	Epilepsy	Stroke	AD	PD	MS	ALS
Prevalence[3] (rate/1,000)	7.1	10	67 for > age 65	9.5 for > age 65	0.9	0.04
No. US patients (in millions)[a]	2.098	2.956	2.459	0.349	0.266	0.012
No. relative to epilepsy	—	1.409	1.172	0.166	0.127	0.006
2007						
NIH funding[2] ($ in millions)	$145	$288	$411	$143	$149	$40
$ Relative to epilepsy	—	1.986	2.834	0.986	1.028	0.276
$ Relative to epilepsy adjusted for relative prevalence	—	1.410	2.419	5.941	8.091	45.977
2010						
NIH funding[2] ($ in millions)	$161	$391	$529	$172	$151	$59
$ Relative to epilepsy	—	2.429	3.286	1.068	0.938	0.366
$ Relative to epilepsy adjusted for relative prevalence	—	1.724	2.804	6.436	7.385	61.077
2011 (estimated)						
NIH funding[2] ($ in millions)	$134	$337	$450	$154	$133	$47
$ Relative to epilepsy	—	2.515	3.358	1.149	0.993	0.351
$ Relative to epilepsy adjusted for relative prevalence	—	1.785	2.865	6.922	7.819	58.500

AD = Alzheimer disease; ALS = amyotrophic lateral sclerosis; MS = multiple sclerosis; PD = Parkinson disease.
[a] Number (millions) of patients in the United States in 2005.[3]
[b] Funding for fiscal year 2010 includes projects funded by regular NIH appropriations as well as NIH funding from American Recovery & Reinvestment Act accounts.[2]

funding was listed in the NIH RePORT[2] with reliable estimate for the number of cases in each disease category across the lifespan in the United States.[3] Because accurate prevalence estimates could not be established for several disorders reported (i.e., traumatic brain injury, spinal cord injury, and Tourette syndrome) and because prevalence estimates were available only for individuals under 21 years of age for some disorders (i.e., autism spectrum disorders and cerebral palsy), those conditions were not included in this analysis. Similarly, migraine was not included because it is not listed individually in the NIH RePORT.[2]

RESULTS Based on the data (table), stroke is the most common neurologic disease, followed by AD and epilepsy, all of which have between 2 and 3 million sufferers. The 3 remaining conditions, MS, PD, and ALS, are far less prevalent, with between 12,000 (ALS) and 350,000 (PD) sufferers. Current NIH spending appears commensurate for stroke and AD, which have the highest level of NIH funding. In contrast, epilepsy, the third most prevalent condition, obtains less funding than all but one condition (ALS), and has approximately equivalent funding as 2 conditions that are approximately 1/6 as prevalent. Overall, the funding disparity for epilepsy has worsened since 2007.

DISCUSSION The data demonstrate a persistently lower funding of epilepsy compared to other major neurologic disorders based on their relative prevalences. Further, the situation for epilepsy has deteriorated since 2007. The NIH does not expressly budget by category, and annual estimates reflect change as a result of science, actual research projects funded, and the NIH budget. The reason for lower funding of epilepsy cannot be due to relative prevalence (table). The mortality of ALS and the increasing prevalence of AD could influence their relative funding. In contrast, lower funding for epilepsy may relate to the fact that approximately 2/3 of persons with epilepsy achieve reasonable seizure control. Even with this consideration, the prevalence of treatment-resistant epilepsy is double that of MS and PD. Epilepsy has a high mortality and morbidity,[4–13] which is at least comparable to the other neurologic disorders. In addition, epilepsy has a higher incidence in children than these other disorders, which arguably leads to greater disease burden due to cumulative effects across the lifespan.

Since the disparity in funding for epilepsy is not due to lower prevalence, mortality, or morbidity, what may account for it? Factors that might potentially contribute to the lower NIH funding could include the processes of review and funding: 1) a consistently poorer scientific quality of epilepsy grant proposals, 2) inequality in epilepsy representation and expertise on the NIH review panels in a process that pits one disease against another, 3) allocation of funding by Congress, 4) more effective lobby activities to promote research funding for the other diseases, and 5) a poorer, more disadvantaged patient population. The contribution of these or

other possible factors is unclear. Thus, the cause remains uncertain.

Our governmental funding for medical research should be allocated based on the impact of diseases on US citizens. This becomes increasingly important during periods of budgetary restraint. Funding for biomedical research should not be left to imprecise processes. There should be a direct link between the impact of disease on the US population and relative funding for research by the government. Further, funding and its effects should be closely monitored so that adjustments can be made to maximize application of available funds. When funding disparities exist across diseases, the reasons should be transparent. Unfortunately, the present funding disparity means that patients with epilepsy will have less opportunity for research to alleviate their suffering and that they are more likely to continue to have increased rates of death,[4–6] injury,[7] cognitive impairment,[8,9] depression,[10] suicidality,[11] psychosocial isolation,[12] unemployment,[12] and impaired quality of life.[13]

AUTHOR CONTRIBUTIONS

All authors were involved in drafting/revising the manuscript for content.

DISCLOSURE

Dr. Meador serves on the editorial boards of *Neurology®*, *Behavior & Neurology*, *Epilepsy and Behavior*, *Epilepsy Currents*, *Epilepsy.com*, and the *Journal of Clinical Neurophysiology* and on the Professional Advisory Board for the Epilepsy Foundation; has received travel support from sanofi-aventis; and received research support from GlaxoSmithKline, Eisai Inc., Marinus Pharmaceuticals, Inc., Myriad Genetics, Inc., NeuroPace, Inc., Pfizer Inc, SAM Technology Inc., Schwartz Pharma (UCB), the NIH/ NINDS, and the Epilepsy Foundation. Dr. French has served on scientific advisory boards for UCB, Johnson & Johnson, Eisai Inc., Novartis, Valeant Pharmaceuticals International, Icagen, Inc., Intranasal Therapeutics Inc., Sepracor Inc., and Marinus Pharmaceuticals, Inc.; has received funding for travel from UCB, Kyowa Hakko Kirin Pharma, Inc., Eisai Inc., Johnson & Johnson, Valeant Pharmaceuticals International, and GlaxoSmithKline; serves as an Associate Editor for *Epilepsy Currents* and the supplements editor for *Epileptic Disorders*; is president of the Epilepsy Study Consortium, which receives money from multiple pharmaceutical companies; 25% of her salary is paid to NYU by the consortium; and she has received research support from SK Pharma Co., Ltd., Valeant Pharmaceuticals International, Pfizer Inc, UCB, Eisai, Johnson & Johnson, the NIH, and the Epilepsy Research Foundation. Dr. Loring serves on scientific advisory boards for the Epilepsy Foundation; serves on the Steering Committee for the NINDS Common Data Element Project, as Consulting Editor for the *Journal of Clinical and Experimental Neuropsychology* and for *Epilepsy Research*, and on the editorial boards of *Epilepsia*, *Journal of Pediatric Epilepsy*, and *Neuropsychology Review*; serves as a consultant for NeuroPace, Inc. and UCB; receives publishing royalties for *Neuropsychological Assessment, 4th ed.* (Oxford University Press, 2004) and *INS Dictionary of Neuropsychology* (Oxford University Press, 1999); estimates that 50% of his clinical effort involves neuropsychological testing including Wada testing; receives research support from the NIH/ NINDS, Epilepsy Foundation, and UCB; and receives travel reimbursement from the NIH. Dr. Pennell serves as a contributing editor to *Epilepsy Currents* and on the editorial board of *Epilepsia*; has received research support from the NIH, the Milken Family Foundation, the Epilepsy Foundation, UCB, and Marinus Pharmaceuticals; has received travel reimbursement from the NIH, the Milken Family Foundation, the Epilepsy Foundation, American Epilepsy Society, and the National EpiFellows Foundation; and serves as a volunteer member of the American Epilepsy Society Board of Directors and as chair of the Professional Advisory Board for the Epilepsy Foundation.

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